

COMMUNITY PARTICIPATION IN ESSENTIAL NATIONAL HEALTH RESEARCH

Prepared by Susan Reynolds Whyte
for the Working Group on Community Participation

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Introduction

Community participation in health has been a major policy theme since the 1970s and was a fundamental principle of the Alma Ata Declaration of 1978. Twenty years later, it is still considered an essential part of health development, but there is growing recognition of the fact that community participation is not a simple matter.^{1, 2} Community participation is also a guiding principle of the Essential National Health Research strategy. The community is considered one of the three major stakeholders in ENHR, and its participation is declared an important part of the ENHR strategy.³

Despite the importance attributed to it, we have little systematic knowledge of how community participation actually functions, or could function, in ENHR. Is it merely lip service to a nice idea? What is really done in the name of community participation? In order to address these issues creatively and critically, the Council on Health Research for Development (COHRED) commissioned a study to examine how community participation has been defined, understood and practiced in countries that have launched ENHR. As in all such studies, this one raises as many questions as it gives answers. It also provides some thought-provoking glimpses of the problems and potential of community participation. By addressing the questions, we aim to reinvigorate the concept of community participation.

To that end, we propose that:

- *Community* be understood not just as a neighbourhood, but pragmatically as any group of people whose interests are at stake in a particular issue.
- Community participation in ENHR is basically about the role of people in research - as direct or indirect beneficiaries, users, and subjects. The relationship between research and the public can take many forms.
- Communities are not static, but interact dynamically with researchers and policy makers. They should be seen as part of reciprocal relationships and processes, rather than as restricted groups with set characteristics.
- Participation has to start by communicating research and policy issues in ways that are meaningful in the particular reality in which people live. One of the greatest weaknesses of ENHR so far has been the failure to inform people about research findings.
- Involvement of researchers in communities is one of the most important forces that link research to action, because communities press for the kind of research they can use.

The study

The study was carried out by a working group, set up as a COHRED initiative, by the Task Force on ENHR Competencies. In the spirit of COHRED, it was carried out at the country level by national researchers, networking in their own countries, who came together to exchange experiences in an international forum.

- The **focus** was on community involvement in the various elements of ENHR (promotion and advocacy, priority setting, etc.), as well as on community participation in research itself.
- The **goals** were to examine what had actually been done in the name of community participation, to discuss problems, and find productive ways of including the third stakeholder in ENHR.
- The **methods** included document review, interviews with key informants, focus group discussions, and, in one case, a small-scale survey.
- The studies were carried out in five **countries**: Bangladesh, Guinea, Philippines, Trinidad and Tobago, and Uganda.
- In addition to the final report itself, the **output** includes national reports, national workshops, a chapter in a forthcoming COHRED publication for the year 2000 International Conference on Health Research for Development, and, hopefully, other user-friendly channels of communication for messages and the discussion of issues.
- The study is intended as part of a **process** of reflection and debate, not just words on paper (or on computer screens). Thus, your input is needed!

Who is the third stakeholder in ENHR?

A basic principle of ENHR is that it involves a partnership between three groups of actors: policy and decision makers, researchers, and communities. Who or what is the third party? Careful reading of *ENHR: A Strategy for Action in Health and Human Development* shows that other terms are sometimes substituted for 'community': the public, the population, people in general, users of health services.³ From reading COHRED publications, therefore, we see that the term 'community' has many implications.

In this study, researchers were invited to look pragmatically at what community appears to mean in the ENHR context within their country. Some of the more significant conceptions were as follows:

- *A geopolitical unit:*

Community refers to the inhabitants of a locality, administered as a unit. It assumes common conditions, activities, and problems, and often a sense of solidarity. It can be described in terms of social structure (local council, school, circle of households, etc.)

- *People who share a common interest, occupation, or cause:*

Community in this sense is not localised. Members of trade unions, language, ethnic, religious groups, or advocates of family planning may not live in the same place, but they have, at least in some respects, a sense of common identity. They may or may not be organised as a group.

- *People mobilised around a given activity or resource:*

This is a dynamic view of communities that come into being in different situations. What they have in common may be conflicting interests in a resource, rather than a harmony of views.

- *Target group of projects or policy:*

The community is the category of people that researchers or policy makers want to do something for, to, about, or with. Often researchers, policy makers, or administrators use the term to refer to those they are aiming at: 'the masses', 'the grass-roots', 'the poorest of the poor', the marginalised, the users of health services. Community may be shorthand for the subjects of a research project (pregnant teenagers, TB patients).

Community is a broad, friendly term, and generous conceptions can be useful. But they can also become hollow and contribute to fuzzy thinking. For ENHR purposes, it helps to specify what kind of community we are talking about. ***We suggest a pragmatic approach: community is what community does. A community is defined for a purpose and in relation to other stakeholders in a particular situation.***

What does community participation in ENHR mean?

Community involvement encompasses a wide range of modalities.⁴

- *Co-option and compliance:*

People participate by being dutiful subjects of research. They answer questions, keep appointments, give samples, and provide logistical support for researchers in the field in the form of food and shelter.

- *Consultation:*

The community is invited to present 'the people's perspective' on matters of interest to researchers. This is usually done in the early stages of research planning and may be a one-time exercise.

- *Cooperation:*

Members of the community are involved in planning and execution of research. They may have an influence on what research is done and how. In some cases they help to collect data.

- *Co-learning:*

The community acquires new knowledge and skills from the research, through dialogue or through involvement in the implementation process.

- *Collective action:*

Together the researchers and community (including policy makers) take action to bring about change. Such action relates to research in two ways: it builds on new knowledge generated by research and the process of implementation itself is a learning experience.

All these modalities are used in the context of ENHR, although not necessarily all at once nor in that order. Very often, however, communities are not meaningfully involved. There may be good reasons for this. The issue we need to address is what kind of involvement is useful, efficient, or valuable in what kind of situation? It may well be that communities are more interested in the opportunity to make use of, and learn from, research, than in executing it. Yet feedback on research results to the subjects themselves or to a broader public is rarely provided. It is all too common to hear remarks like: 'A professor came here and took my urine - but we never heard anything more about it.'

The linear and mechanical model of community participation suggests that communities articulate their problems, and help to carry out relevant research that can have an effect on policy. But what we are learning is that effective involvement is a matter of reciprocity and continuous dialogue, with different forms of participation and influence exerted in several directions. People need to be informed about research and policy, if they are to be stakeholders in ENHR. Researchers have to work with the media, advocacy groups, health workers, and relevant organisations in order for community participation to be meaningful in the sense of co-learning and collective action.

What levels are we talking about?

The level at which communities are to be involved - national, district, sub-district, neighbourhood - is too often unspecified.

- At the **national** level, the community may consist of national/international NGOs concerned with development (as in Bangladesh), advocacy or pressure groups (Health Action International), support groups (the Diabetes Association of Trinidad and Tobago), television viewers or newspaper readers. At this level, the community may be just another term for civil society, the public, users of health services.
- At the **district** or **sub-district** level, the community may be local officials, health workers, "grass-roots" staff of large NGOs, community-based organisations, religious leaders, or a focus group drawn from different neighbourhoods within the district.
- At the **neighbourhood** level, we may be talking about women who use certain water sources, members of a religious congregation, the catchment area of a health facility, those employed at a workplace, etc.

Levels of community participation in Uganda⁵

Since Uganda adopted the ENHR strategy in 1991, it has tried to involve communities at several different levels. At the first national level workshop, NGOs were invited to represent the people with whom they worked. When a national task force was created to consult on research priorities, a person from the Uganda Community Based Health Care Association was included.

The actual consultations were made at district level. Three districts were selected and meetings were held with the district health teams and planning committees; the latter included elected representatives of constituencies in the district. With the help of these district officials, communities were chosen for focus group discussions on health priorities for research. These communities turned out to have much broader views of health problems than researchers did. They were concerned about low family income, bad roads, lack of markets for their produce, harmful cultural practices, and inadequate health facilities, as well as specific health problems, like malaria and AIDS.

Given Uganda's policy of decentralisation, the ENHR coordinating team is now trying to develop the capacity to make research priorities and carry out relevant research at district level. District Health Teams are encouraged to involve stakeholders in defining research problems that are district specific. In several pilot districts, members of the health team are being supported to carry out such research, analyse results, disseminate them, and use them for planning.

At neighbourhood level, Uganda has many examples of long-term relations between researchers and localities. A researcher who is familiar with an area is in a good position to work with residents to define problems and experiment with solutions - as was the case with the community-based tsetse control project described in the Uganda study.

Who speaks for whom?

Thinking about community in this way raises the issue of representation. Who represents the community at a national priority-setting workshop or in a village meeting? Who speaks and who remains silent? In one African country, NGOs and elected assembly members were chosen to represent the people at a national priority-setting exercise; in another the attitude seemed to be: 'They are just politicians - they don't represent the people!'

There are no simple answers here. All representation is partial. We often hear how important it is to reach the 'real grass-roots' or the 'poorest of the poor'. But in practice, it is often people whose work brings them into daily contact with marginalised groups who represent their interests to researchers and policy makers. What is important is whether the parties involved are the best to reach the goals you are aiming at in a particular situation.

- **Organisations:** Each country has its own story about what might loosely be called civil society — that collection of non-state organisations, which includes national branches of international development or welfare organisations, community-based organisations (CBOs), groups based

on religion or occupation, advocacy groups, and others. Some groups clearly represent interests and act on behalf of their members — as when an association of businessmen elaborates programmes dealing with health issues that have an impact on their business. Others are development and service organisations that speak for their clients or target groups.

- **Elected or appointed officials:** While senior level government officials might be policy makers, those at middle and lower levels are often seen as the legitimate representatives of, and spokespersons for, their communities. Even when there is doubt about how representative they are, it is usually advisable to try to include such officials. They can facilitate or obstruct.
- **Health workers:** On the one hand, health workers are a community in themselves; on the other, they are part of the community in which they work, and are well placed to represent the people and problems they confront every day. But we should remember that their interests might not fully coincide with those of their patients!
- **Local leaders:** In community work the importance of opinion leaders is recognised. They not only speak for and represent the community, but exercise power and exert influence — sometimes because they are wealthier, control important resources, are more educated and articulate — but sometimes because of personal qualities like moral authority, intelligence, or energy. Opinion leaders are sometimes seen as a problem by researchers: one research project in Guinea stressed that focus group discussions excluded local leaders because they tended to dominate.⁶ But another project in the same country emphasised how important it was to use local leaders as channels for reaching the target group of the project.^a
- **Men:** In many countries, women's voices are seldom heard in public. Men speak for women. Where they are better educated and have more time and contact with influential people, men are more likely than women to represent their community and to participate in the various ways that people can be involved in research. This can be disadvantageous for women and impractical in so far as women's views are relevant to the problem at hand. But there can also be a positive side to involving men more thoroughly in health issue — especially where researchers and policy makers have tended to see family health as the sole responsibility of mothers.

As researchers and policy makers address some people and not others as representatives of communities, they may reinforce existing forms of organisation or help to create new ones. Addressing problems of inequity in health means asking whose voice is not being heard. Long-term field researchers or thoughtful service providers may be helpful in pointing out who has not spoken up in a given context.

a Recovery of children who dropped out of vaccination in the sub-prefecture of Maferinyah. See the Guinea country study.¹²

NGOs and the grass-roots in Bangladesh⁷

With a population of about 123 million people, the vast majority in rural areas, Bangladesh has faced a real problem of community representation. Nearly half of its citizens live in poverty and only 45% of those 7 years and older are literate. The situation of women is of special concern. Local government structures are weak in terms of resources and development functions. In this setting NGOs have played an enormous role – first in social welfare activities, and later in promoting community participation in development. It is said that Bangladesh is a country of NGOs. In the field of health and population alone, there are over 2,000 registered non-governmental organisations.

In the process of implementing ENHR, an NGO, the Bangladesh Rural Advancement Committee (BRAC), was a key player and currently houses the ENHR Secretariat. In national workshops on ENHR, NGOs were well represented – in fact, they constituted the largest category of participants. Likewise, the National Forum of ENHR, B and the ENHR, B Working Group have a weighty proportion of NGO representatives. The assumption seems to be that NGO involvement ensures community participation. The question is: in what sense do NGOs represent communities?

The obvious answer is that NGOs are a community of interests and they represent themselves in the ENHR process. But group discussions held in connection with the Bangladesh study suggested more concern with how the NGOs might represent their grass-roots target groups. One view was that there was indirect community participation in ENHR because the NGO representatives belong to organisations that work directly with the grass-roots level people and therefore reflect their health needs and perspectives. A more critical view was that NGO executives are the ones to attend workshops and sit on committees; they have little direct interaction with poor village people. Lower level (frontline) NGO personnel might be better representatives.

Is community participation relevant to all kinds of research?

A distinction is often made between community oriented and biomedical research. The assumption is that community participation is mainly relevant to the first kind. After all, lay people can hardly be expected to involve themselves in highly technical issues, which they are incapable of understanding. What is fundamental for community participation is that people should see in the research some kind of potential for, or relevance to, their lives. This is easiest when the problems addressed are at the level of experience—availability of health services, feeding of children—rather than at the level of experiments involving microbiology or pharmacology. But here too, we need to be more open-minded about what community participation means.

- **Operational studies and action research:** Most of the examples of community participation in actual research projects were of this kind. The cases described were as much about taking action to solve problems as they were about research in the strict academic sense. Joint explorations of local conditions were followed by systematic attempts to find new ways to manage problems. This kind of learning for a purpose makes sense for the “research subjects” who are directly involved.
- **Epidemiological and survey studies:** At first glance, there is not much scope for community participation in quantitative studies. Sometimes members of the community under study are trained as enumerators. But beyond being dutiful respondents, most people are not involved. Yet if greater efforts were made to disseminate the results of such studies, both to the respondents and to the interested public, there could be a broader level of involvement in the sense of co-learning.
- **Health systems research, policy analysis, community studies:** Social science research—whether on health economics or perceptions of diarrhoea—is not necessarily operational research. Planning and data collection are usually done by the researcher; those being studied do not become co-researchers. (In fact, in ethnographic research the idea is that the researcher participates in people’s projects, rather than they in the researcher’s.) Nevertheless, researchers could ask themselves whether their work is relevant to any community beyond the academic community of colleagues. Identifying an interested group—communicating in such a way as to arouse interest—is also a form of relationship between researchers and the third stakeholder in ENHR
- **Basic or clinical research on specific diseases:** In many countries, the most common type of health research is biomedical. If a country has set its health research agenda using the ENHR strategy, this biomedical research is likely to focus on specified priority diseases. What kinds of community involvement, if any, can occur here? There are examples of lay persons in localised communities (what we call *neighbourhoods*) helping to collect biomedical data, and even taking part in analysing it.^b But other kinds of communities can be addressed as well. Primary health care workers may be the most important group to collaborate with in discussing disease research. In Trinidad and Tobago, researchers consulted them when they worked out treatment guidelines for common diseases. In some countries, there are advocacy/support groups for people with chronic diseases or disabilities – HIV/AIDS, diabetes, heart disease. Their involvement could allow a form of community participation.

^b In the Philippines report,¹¹ a community-based malaria intervention project is described, in which lay people learned to identify and collect certain types of mosquito, as well as help conduct and read blood smears.

Another kind of community participation in Trinidad and Tobago⁴

In Trinidad and Tobago, as in other countries who are members of the Caribbean Health Research Council (CHRC), community participation has not been a central aspect of health research. In 337 papers presented to regional scientific meetings over the last three years, none mentioned consultation with communities in the selection, design or implementation of the research. But in that same period, a drama has been unfolding on the national stage that reminds us that community participation can take many forms.

When the country was selected as a possible site for phase II HIV/AIDS vaccine trials, external research collaborators gave a mandate to national researchers at the Medical Research Foundation to make preparations in case the Government should give its consent to the trials. What followed might be described as attempts to create a community.

Trinidad and Tobago is a small country of 1.2 million people, with a well-developed media and communications sector. The possibility of the AIDS vaccine trial provoked a lively debate in newspapers, radio and television. A full-page advertisement against the trials was taken out in a national newspaper. The researchers soon realised that many people were not well informed about research, much less about AIDS vaccine trials. The fear that thousands of Trinidadians would be used as guinea pigs was widespread. On television people had learned about the syphilis research on black Americans in Tuskegee, and they realised that research could involve risk and humiliation. AIDS itself was a poorly understood and sometimes divisive issue. Some religious groups opposed any discussion of sexuality. The mandate to inform people about the vaccine trials became the much larger task of communicating about the prevention and treatment of AIDS, the situation of people living with the disease, and the role of research in dealing with it.

With the help of two community consultants, and with support from an international network of researchers and AIDS advocacy groups, steps were taken to reach out to the public. A one-day workshop was held for journalists. The staff of the national AIDS Hotline, which was established early in the 1980s, was trained to respond to questions from the public concerning the proposed vaccine trial. The community consultants appeared on television over several months. There were meetings with professional organisations. Once the issue became widely known, the community consultants and researchers were invited to speak to groups like the Organisation of Science Teachers. Most important, a Community Advisory Board (CAB) was established to advocate vaccine trials, to inform the public, and to act as watchdog for the interests of the public and those who might eventually become research subjects. The CAB consists of 20 people; most represent interested organisations; some are media consultants or people whose lives are touched by AIDS.

The process is on going. Even within the CAB, consensus and respect for difference need to be built. The members have been receiving training in how and what to communicate, and on planning how to go ahead. The Ministry of Health has established an Ethics Committee to review the scientific aspects, as well as ethical issues, of the proposed vaccine trial protocol and to advise the Ministry accordingly. Public opinion is still divided and many people are not yet well informed. But what is important is that research has been brought to public attention.

A community of interests has been established, even though the interests are often conflicting. And an advocacy group is working to promote understanding of the nature and need for research on AIDS. As one of those involved explained: 'It is an educational process to get the community to the point of being able to make decisions about research and to see how research could help.'

What kinds of relationships exist between researchers and communities?

Two dimensions of the relationships between communities and researchers stood out in the examples from our study: duration and demand.

- **Time frames:**

Most health research is of short duration. Researchers working with a patient group or geopolitical unit are happy if they finish their data collection and analysis before their funding ends. Because the time frame is short, there is usually little reciprocity in this type of relationship. The researcher has no obligation to the community in the long run. While communities can be involved, the opportunity for a continuing dialogue with the research subjects is limited. Of course, researchers could use what they learn in a dialogue with another community (the newspaper-reading public, students at a school for paramedics, etc.). But most often, researchers feel they have met the ethical obligation to disseminate the research results by submitting a report to the sponsors, to colleagues, or perhaps to a national institution.

Some research projects are embedded in a long-term relationship with a community. This is the case where research stations and community health training programmes (Maferinyah in Guinea, Matlab in Bangladesh, etc.) have been established.^c In some cases a series of research projects are linked to a long-term epidemiological study, where cohorts are followed over many years. These offer better opportunities for people to get to know about the research. They know where they can find the researchers again. Often such sites are associated with health care services, so that people associate the research with some kind of benefit to their community.

- **Community demand for research:**

It is not usually the case that communities spontaneously ask for research to be done. It is a fundamental fact about the relation between researchers and communities that researchers generally take the initiative. Communities—or the public in general—are seen as the ultimate beneficiaries of research, but not as immediate users who might actually request it.⁹ Yet this can happen, and could happen more frequently, if the structures were in place to acquaint communities with the potential uses of research and to facilitate contacts.

Development projects are probably the most important users of research in many countries. Those who implement projects need operational studies, and those who benefit from the project see an immediate use for such work. Where there is a high level of dependence on development assistance, the initiative to commission a study often comes from those who provide the funds. Occasionally local development efforts request technical support to carry out studies, as did the PACODET project in Uganda.¹⁰ In any case, communities are users of research to the extent that they link the creation of knowledge to the solution of concrete problems that they experience.

^c The InDepth network brings together longitudinal research projects based at 20 fieldsites in sub-Saharan Africa.

A user orientation towards research must be sensitive to community problems and interests—the areas where specific groups might see a need and use for research. **Health workers** may want to systematically gather information about a problem that arises in the course of their work. **Advocacy groups** may be interested in research as a basis for promoting legislative or administrative change. In South Africa, the Reproductive Rights Alliance presented research results to the Parliamentary Portfolio Committee on Health in support of their argument for legislative change.^d In many countries there is a growing number of support/interest groups for particular diseases or conditions: for people with AIDS or other chronic diseases, disabilities, alcohol and drug problems. The Diabetes Association of Trinidad and Tobago wanted certain research topics studied. They knew that research had been undertaken in their country on this priority health problem and wondered why no researcher had ever contacted them.

The issue of how researchers and communities relate to each other is, in part, a question of structures and institutions. It is not necessarily the case that one overall national coordinating body should have responsibility for fostering such relationships. But part of the task of an effective mechanism for research management could be the identification of structures that might support contacts between the two parties, and that could cultivate communities as users of research. Existing community health research and training programmes would be an obvious place to start.

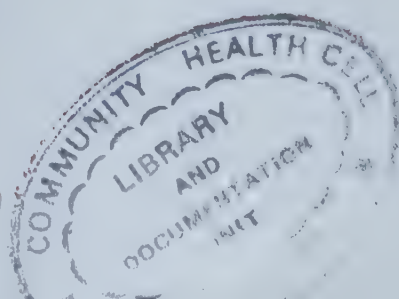
University/community alliances in the Philippines¹¹

The Philippines has a long tradition of community organisation and development work, as well as a rich assortment of NGOs. From both of these sources flow positive attitudes and experiences about people's involvement in the solution of their own problems. There also seems to be a widespread acceptance that operational research should be a part of these efforts. But a real dialogue takes time to develop, and appreciation of the process needs to be instilled in future researchers as part of their training. To this end, several medical schools have established programmes in community participatory development.

One of these is the Zamboanga Medical School Foundation, which collaborates with the Pediatric Research Center for Mindanao, the Regional Health Office of the Department of Health, and the Local Government Units in Region 9. Medical students learn community participation strategies in their problem-based medical curriculum. They are assigned to rural health units in underserved areas and they have a commitment to work with cross-sectoral community participation, not just focusing on narrow medical issues. The goal is to develop participatory intervention programmes for priority health problems.

This is a long-term alliance between a training institution and a geopolitical community. Students rotate through the programmes, junior students overlapping with seniors, in order to maintain continuity and avoid repetition.

^d See their website: <http://www.healthlink.org.za/rr>



What are the expectations and trade-offs of community participation?

Although researchers and communities may share a long term commitment to improvement and even to equity in health, in the short term they usually have divergent interests and expectations. The work of researchers is to create new knowledge, and they are accountable to their colleagues and their sponsors. For them, some degree of community participation facilitates research in terms of compliance and logistics. Many appreciate the way that involvement of communities poses challenging and socially relevant problems. But it also demands resources, especially time, to carry on dialogues and attend to the (often conflicting) interests of community members. It is a source of bother that community expectations do not correspond to research goals and methods. Researchers need to understand that this is not just an obstacle, but an issue deserving careful, scholarly attention.

By and large, communities are less interested in knowledge for its own sake; they are more concerned with its possible relevance to their lives. There are great differences between countries in the extent to which members of the public grasp the concept of academic research, even, as we saw, in a country like Trinidad and Tobago where the level of education is relatively high.

Nevertheless, there are many indications of positive expectations on the part of community members. Initially there is often a hope of material benefits and an anticipation that the Government or researchers will provide solutions to the problems under investigation. There is a desire to help oneself, one's family, or others; and for some people, there is a genuine wish to acquire new skills and knowledge. In so far as researchers are significant outsiders or powerful elites (doctors, professors), there is an opportunity to gain influence by cooperating with them. At least, it is better not to offend them.

But there are trade-offs for community members too. Demands are made on their time and material resources, often with no compensation. If their efforts seem to bear no fruit for themselves, they may feel bitter or lose interest in cooperating. At worst, they may feel exploited. Our country studies showed many examples where communities felt that nothing had come out of the research. They never even heard anything about what the researchers discovered. While not all research projects can feed back results directly to their research subjects, there is an issue of public accountability and communication here that is too often neglected.

Community expectations in Guinea¹²

The Guinea country study involved interviews with 160 residents of four rural areas, concerning their experiences and views of community participation in research. This required explanation, since the concept of research is not familiar to many people in rural areas of Guinea. Almost two thirds of the respondents said that no research had been done in their area. But once they understood, the majority of respondents expressed expectations about their role and that of researchers. When informed and mobilised by local officials, residents should be ready to assist in answering questions, helping researchers, and providing food and lodging. But finding solutions to their problems should be the responsibility of the researchers and the authorities. The community members wanted medicine and health facilities.

A different pattern emerged in one of the localities studied, Kissidougou. Action research had been carried out in connection with the establishment of a health insurance programme. PRIMA (Partage de risques maladie) was a collaborative effort between local residents, the Government and GTZ, the German Development Agency. GTZ had been working in the area, and had financed a health centre. A German volunteer started a maternity centre. Although these were not strictly part of PRIMA, many people associated the action research with the health insurance scheme and the new facilities. The tangible results were important. In contrast, respondents in areas where research had not brought any advantages, expressed disappointment.

But the new health services were not the only result. The establishment of PRIMA was a process in which participatory research methods were used to explore health problems and resources together. People who had been involved were more articulate about their health problems than respondents in the other localities. A climate of dialogue was created, in which they learned to discuss, clarify their ideas, and reflect on their problems. Their view of community participation was correspondingly different. They expected researchers to define strategies together with them and to collaborate with them in putting research into action.

One final point about community expectations in Guinea is important. Although people wanted concrete benefits, they also wanted information and feedback on what the researchers had found out. And they thought the authorities should insist on researchers sharing their knowledge.

There is a simplistic view that communities have problems and expectations that can be identified for researchers once and for all. But those who have worked with communities emphasise that community participation is a process that develops over time. Expectations change as communication develops, no matter what kind of community we are talking about.

How can community participation contribute to equity in health?

In the broadest sense, community participation is about the relation between research and the public. If the first step towards equity is to draw public attention to the dimensions of inequity, then communication of research findings about health inequities is essential. But what kind of communication is most meaningful to whom? Traditionally, epidemiological surveys are powerful ways of supporting arguments put to politicians; numbers are seen as facts. Yet research, in which elements of community participation are strong, may be equally convincing -- or even more effective in motivating change. Communication that incorporates the voices of marginalised or struggling people, especially if they are active agents looking for allies, adds a human dimension to the movement for equity. Journalists are experts in extracting the personal touch of a pitiful case; that is not what we mean. Communication highlighting research on inequity should show the dimensions of the problems as they are experienced and managed by a community of social actors.

It is not simply a matter of communicating to the public in a general sense. Focusing on the participation of marginalised groups in research can involve them more actively in the struggle for equity. Equity is not just a question of giving vulnerable groups opportunities for improved health, but also of supporting them in creating and taking opportunities. The problem is that the most vulnerable are often least likely to participate. Creating equity means helping them to find allies in a community of action and advocacy, rather than focusing on a limited vision of community as only those who are the 'poorest of the poor.'

How can community participation link research to action for development?

Linking research to action is often seen as a matter for researchers and policy makers. It is assumed that policy is the key to action, and that research must feed into policy. However, community participation can be a potent force here as well, in at least three ways.

- Community involvement encourages research for action, since communities are most interested in research that is relevant to problems as they experience them. They want useful research, and they are particularly keen on operational research where new knowledge is implemented and tested.
- Education of the public/community can push policy makers into action. Public pressure is important in democratic, and even in undemocratic, societies. Dissemination of research results, creating awareness of health problems, inequities, and possible solutions, can contribute to the momentum for change.
- Participation can empower people to act on their own behalf. To the extent that community involvement helps people to articulate their problems, to learn, to acquire and practice new skills, to make allies—they are better able to be active and responsible. This does not mean that communities should be expected to solve their own health problems. But it recognises that they are not simply passive recipients of health services, and entirely dependent on the knowledge of experts.

Towards a learning and innovative coalition

Many researchers think that community participation is about listening to “the people” (or the organisations that purport to represent their interests). In order to truly make a difference in linking research to action and working towards equity in health, the relationship between communities and the other stakeholders must be thought of as a continuing process of dialogue. It is by reciprocal communication, not one way listening, that coalitions between researchers and communities can be built. Such partnerships would be learning coalitions to the extent that all partners acquire new understanding. And they would be innovative to the extent that they attempt to define common goals and discuss means of achieving them. Such coalitions would require greater flexibility and a more long-term approach. Instead of thinking in terms of conventional individual research protocols with set objectives, researchers might have to think in terms of phases, or a series of projects, or a framework for continuing exchange.

Attempting to establish dialogue puts an obligation on researchers to communicate about their research in appropriate ways. Disseminating findings should be part of Essential National Health Research. One possibility would be to make this part of an ethical code, just as informed consent or protecting research subjects. Another strategy would be to better equip researchers to perform this task by training them in some of the necessary communication skills. In many countries, collaboration with the media is the most common strategy. Workshops can be held for journalists, and they can be hired to help publicise research findings. Whatever strategy is adopted, there should be channels for community members to express their views and ask questions. Where people have access to the media and good communication infrastructure, radio call-in shows, telephone hotlines, and health advice columns to answer readers' questions are all possibilities. Face to face communication will be the primary strategy in many settings; and a single dissemination workshop is not sufficient. Researchers need to meet communities in a variety of situations over time, so that there are real opportunities to learn to communicate.

Essential National Health Research is based on the principle that researchers are accountable to the society in which they work. This ethic needs to be conveyed and discussed together with the learning of research skills. Putting medical students through a community medicine programme is a start, but is not sufficient. University curricula should include training on relationships between researchers, policy makers and the public. Future researchers need to learn about the dilemmas of accountability (to whom? about what?) and about different ways of relating to different kinds of communities.

The organisations of civil society may have a special role to play in coalition building. They have an institutional character that persists over time and provides a framework. If they emphasise internal dialogue, as well as external communication between leaders and researchers, they could be genuine representatives in a coalition. But structures need to be put in place to encourage relationships between organisations and researchers, and here policy makers could take steps to establish an organ or a channel of communication.

One possibility is what is known in some North American and European countries as "science shops". They function as a link between universities and communities in the larger society. Non-commercial organisations define problems for which research is needed, and contact the science shop, which links graduate level students and their supervisors with these potential users of research. In other words, communities are recognised as consumers of research and young researchers are given the opportunity for apprenticeship with organisations that want their services. At the University of Copenhagen, the science shop office is run by experienced students, who make contacts with all kinds of agencies from patient organisations to sections of local government. They help students negotiate research projects and ensure that the results are disseminated to the clients in ways that are useful.

The last decade of Essential National Health Research phrased the ideal of collaboration between communities, policy makers, and researchers in terms of links between stakeholders. The term stakeholder suggests that a party has an interest in an enterprise, something to gain or lose. The image of a triangle of stakeholders conveys a sense of rigidity, as if the interaction were a series of linear communications and tradeoffs between the three groups. 'Coalition' has another flavour. It is more action oriented, suggesting issue-based alliances, debates and negotiation between disparate parties. Coalition members sometimes have conflicting interests, but commitment to a coalition implies an effort to accomplish something together despite the differences. In the next decade of health research for development, it may be most fruitful to think of community - researcher relations as coalitions for defining problems and learning how to solve them.

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